

HCOU CARES

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Introduction

United States Special Olympics athlete Joe Kaczynski loves running and is committed to training and building the bond with the sport that “makes him feel alive,” according to a Special Olympics article on the ESPN website. “Running is the most important part of my day, because it's the No. 1 thing I love,” Joe says. “It's all about heart and desire (Smith, 2017).”

How do most people with intellectual and developmental disabilities (I/DD) discover something that “makes them feel alive?” People who know them best such as family members or caregivers supporting them in their group home are often influential in exploring and facilitating the wishes of people in their care. They understand how the person communicates best, such as through pictures or the person’s own sign language. They also know how to help the person understand information, for example educating them on their health care issues. Effective communication is the foundation for ensuring that people with I/DD have a voice, allowing them to choose what is important to them. This edition of HCQU Cares is dedicated to increasing the caregiver’s ability to provide people with I/DD the opportunities to attain their hopes and dreams and to be successful in achieving an Everyday Life.

Reference:

M. Smith “Born to run: ‘It's all about heart and desire.’” ESPN, 23 Mar. 2017, www.espn.com/specialolympics/story/_/id/18985101/special-olympics-world-games-marty-smith-shares-inspirational-run-athlete-joe-kaczynski. Accessed 30 Aug. 2017.



Giving People a Voice at Each Stage of Life through Communication Assessments

By: Rebecca Trigger, RN

Individuals with I/DD participate in society more than ever before, yet many of them have significant communication support needs that remain unmet. Data from the 2011-2012 Independent Monitoring for Quality (IM4Q) Statewide Report for Pennsylvania indicates that “For those individuals who do not communicate using words, there continues to be issues around lack of exploration of alternative strategies. Most individuals (nearly three quarters) that do not communicate using words do not have a communication system in place. When it has been explored and people have acquired systems including devices, individuals have devices that are not in working order and that are not being used across all settings” (IM4Q statewide report, 2011-2012).

The Pennsylvania Office of Developmental Programs (PA ODP) holds everyone’s right to communicate in high regard. Bulletin #00-08-18, Communication Supports and Services, specifies that individuals should “receive the supports they need to improve their ability to communicate across all aspects of life.” PA ODP reaffirmed their commitment to effective communication with the first recommendation from the Information Sharing and Advisory Committee (ISAC) published in the 2016 Everyday Lives: “Values in Action” document, “Assure Effective Communication.” Both of these documents speak to the importance of people with I/DD having the ability to communicate in order to express choice and ensure health and safety.

One way to assure effective communication is through a comprehensive speech and language evaluation. This type of evaluation is usually performed by a speech language pathologist (SLP), a licensed health care professional who screens, identifies, assesses, refers, and provides treatment to persons with or at risk for speech, voice, language, communication, swallowing, and related disabilities. Look for a SLP who is registered with The State Board of Examiners in Speech-Language Pathology and Audiology. The State Board of Examiners regulates the practice and licensure of persons offering speech-language and hearing services in the Commonwealth of Pennsylvania (<http://www.dos.pa.gov/ProfessionalLicensing/BoardsCommissions/Speech-Language%20Pathology%20and%20Audiology/Pages/default.aspx>).

Keep in mind that not all SLPs are experienced with working with individuals with I/DD and/or have knowledge of newer technologies such as, communication devices, iPads and the over 250 apps now available specifically for individuals with I/DD. It is important to seek out SLPs who do have experience with assessments for individuals with I/DD, as certain conditions may have specific communication characteristics that need addressed, such as the social communication impairments often seen in autism. The following questions may assist caregivers to determine if a SLP can meet the needs of a person with I/DD:

- What is your experience in working with people who have intellectual and developmental disabilities (I/DD)?
- With which augmentative and alternative communication (AAC) devices do you have experience working with?
- Are you familiar with the many apps now available for iPads, etc.?
- Are you able to schedule appointments for people with I/DD early in the day or early afternoon?
- Will you travel to group homes/adult day training programs to perform evaluation?
- Do you allow extended appointments to accommodate the needs of someone with I/DD?
- Do you accept [name of individual's insurance carrier] insurance?
- Is a physician's order required for an evaluation and/or treatment?
- Will you train the individuals' family, staff, peers, co-workers, etc. on how to use any augmentative and/or alternative communication devices?
- Will your screening include hearing, speech, language, communication, and swallowing problems, if needed?

People with I/DD can benefit from a functional communication assessment at different stages of their lives, because the results of a communication assessment and implementation of any augmentative and/or alternative communication techniques, such as picture boards, manual signs, gestures, Picture Exchange Communication system, and speech generating devices, are effective only during the stage of life the assessment was performed. Additionally, communication needs can be different at different times of life. For example, according to the American Speech-Language-Hearing Association (Intellectual Disability Overview, 2017, <http://www.asha.org/Practice-Portal/Clinical-Topics/Intellectual-Disability/>), "Individuals with ID continue to develop communication skills beyond the school years. As the person with ID reaches adolescence and adulthood, his or her communication and functional needs change. For example, the teen years place a premium on peer interactions, use of social media, and communication skills needed to optimize acceptance and relationship development. Individuals transitioning from school to vocational settings will need communication skills specific to the work setting, such as talking with co-workers and supervisors, and interacting with customers."

PA ODP requires that individuals have their functional communication needs assessed annually as part of the Individual Support Plan process. Per Bulletin #00-08-18, some of the goals of this type of assessment are to ensure the individual has increased communication in a variety of contexts, increased effectiveness of communication with both familiar and unfamiliar people as communication partners, and has the ability to initiate, maintain, and terminate communication interactions. At times the care team may feel the person communicates well enough, as they understand what is being said, but the effectiveness of communication in all environments, and with a variety of people, is part of the evaluation criteria recommended by the PA ODP.

Caregivers who recognize limitations in communication and consider the impact of a formal communication assessment are assisting the person to increase communication skills. Many times caregivers feel challenged by finding an appropriate communication assessment. It is essential to have an order from the physician for the assessment, so that is the first thing to do. Once the order is obtained, consider these suggestions for how to find a qualified professional to perform the assessment:

How to find a licensed speech-language pathologist?

SLPs work in a variety of settings, including private practice, hospitals, university-based clinics, and schools. There are various methods that can be utilized in locating a SLP who has experience working with individuals' with I/DD;

- The individual's Primary Care Physician can provide a referral and may have knowledge of a SLP who works specifically with individuals with I/DD.
- The individuals' health insurer's "network" listing may provide information.
- The special needs unit in the individual's area may be able to provide information.
- Personal recommendations can be from friends, providers, or other families.
- A search of the local "yellow pages" or an online search under "speech and language pathologists" or "speech therapists" can be performed.
- Professional associations such as the ones listed below can provide information.
 - American Speech-Language-Hearing Association (ASHA, www.asha.org)
 - Pennsylvania Speech-Language Hearing Association (PSHA, www.psha.org)

Once the assessment is completed, the SLP will make recommendations for speech therapy and/or various assistive communication devices, and the individual can be well on his way to having the means to effectively communicate with all people and in all situations.

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American Speech-Language-Hearing Associations, Communication Characteristics: Selected Populations with an Intellectual Disability, 2017, <http://www.asha.org/Practice-Portal/Clinical-Topics/Intellectual-Disability/Communication-Characteristics--Selected-Populations-With-an-Intellectual-Disability/>

Intellectual Disability Overview, 2017, <http://www.asha.org/Practice-Portal/Clinical-Topics/Intellectual-Disability/>

PA Department of Human Services: Bulletin # 00-08-18 Communication Supports and Services, <http://www.dhs.pa.gov/publications/bulletinsearch/bulletinselected/index.htm?bn=00-08-18>.



Communication – An Important Tool for Teams

By: Brian J. Leech, MS, Clinical Educator

Consider the following scenario: Jim, a man with I/DD who has hearing loss, finds himself feeling ill one afternoon. He typically communicates with sign language, although his signing is not always clear, but he usually is able to make his feelings known to others who understand sign language. Joe, a new caregiver, does not know sign language. Jim makes the sign for 'sick' several times over the course of an hour, and Joe asks what he means but is unable to determine what Jim wants. In frustration, Jim throws an empty cup at Joe, who does not know why this happened and does not want to continue working with Jim. So, what went wrong in this situation, and how could it have been avoided?

One of the most effective ways that caregivers support individuals with I/DD is by understanding the person's wants and needs. A key component in understanding wants and needs is communication; it drives virtually all of the interactions that people have with one another. In fact, we are always communicating with each other, even when we don't say a word. This becomes especially important when working with those who have I/DD, as they may not always be able to verbally tell others what they need. The individual may use behaviors as a means of communicating, and if caregivers are not able to understand the person (or vice versa), those behaviors may become challenging. Sometimes, the means of communication that an individual uses is not apparent until caregivers have had the chance to reflect on them. In these situations, it may be helpful for the entire team to think about a plan for ways to improve communication.

In order to provide the best support, caregivers must be able to simply and effectively communicate with the person while exploring ways to help the person be heard and understood. If communication constantly breaks down, both the person and the caregivers become frustrated due to not knowing each other's wants or needs. The person with the challenging behavior is often challenging caregivers to listen and figure out the individual's needs. Fortunately, there are ways that caregivers can work together with the individual to improve communication:

- **"The 18 Second Rule"** – allow at least 18 seconds for the person with I/DD to process and respond to a question or a statement. This gives the person time to think about and understand what was said without putting any pressure on the person or causing undue confusion. If it's been more than 18 seconds without a response, feel free to ask the person if he or she was able to hear and understand the statement.
- **Give direct attention to the person** – avoid doing paperwork, having conversations with other caregivers or housemates, or performing other tasks while the person is talking. This promotes respect and a feeling that others are interested in what one has to say.

- **“Communication Partners”** – people closest to the person and who know him or her best. Communication partners include family or other caregivers, but may also include professionals (such as sign language interpreters). They may also understand the person’s body language, verbal or non-verbal cues.
- **Communication Tools** – these are items that help to facilitate communication between the person and others. These can include the following devices:
 - **Communication Board:** a device printed on paper, cardboard or poster board, or any other format; it lists frequently used words and phrases that are specific to the person.
 - **Augmentative Communication Devices:** electronic devices that can be used by individuals to communicate verbally. These can be in the form of a computer, smartphone, or a tablet that uses programs and applications to help the person communicate verbally.

In addition to understanding the individual with I/DD better, caregivers can also use communication as a means to help the person feel safe and to excel in his or her recovery. A few techniques can help in this regard:

- **Active listening.** When communicating with someone, listening is vital. In active listening, the person who is hearing the speaker is also working to understand the messages being sent. Active listening not only helps to foster understanding, but it also helps to build trust between caregivers and the individual. To use active listening, remember to give full attention to the individual – do not try to do other activities/chores while the person is speaking. Also, it is a good idea to try not to think of what to say while the person is speaking. Instead, restate what the person has said to ensure understanding.
- **Take your time.** Try not to rush conversations with the individual, but take time to clearly state your thoughts. Use simple and direct words, and avoid any professional jargon. If needed, repeat information for the individual if he or she is having a hard time understanding what is being said. This relates well to the 18 Second Rule as described above.
- **Avoid abstract concepts.** Keeping language concrete and simple means that there is less room for mistaken interpretations or misunderstandings that can lead to potentially difficult and/or challenging situations. For example, when sitting down at a restaurant, a caregiver can say, “Let’s sit here,” rather than “Grab a chair.” Keep things simple and concrete and ask yourself, “Could what I’m saying be misinterpreted in some way?” If so, think about how it could be stated more clearly.
- **Validate.** Validating another person’s feelings is an effective way of helping that person feel heard, understood, and accepted. Validation means letting the person know that what he or she is feeling is normal and okay. This is not to excuse unhealthy or dangerous behavior, of course, but to let the individual know that someone is interested and invested in trying to understand his or her viewpoint. For example, when Mary says, “I really miss my Mom,” the caregiver can validate that by stating, “It’s normal to miss the people we love and want them to be around us.” An invalidating statement would be, “Don’t worry about it, you just saw her yesterday,” which can lead Mary to feel misunderstood or to think that others simply don’t care.

Keep in mind that good communication techniques take practice. Nobody can be a perfect communicator at all times, but that doesn’t mean that it’s impossible to help others more clearly understand what we say. Also, listening and attempting to understand the individual is just as important, if not more so, than clearly stating one’s own thoughts and feelings. Effective communication is a two-way street, and by working to improve it, teams and individuals can see fewer challenging behaviors and experience more satisfaction with day-to-day life.

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Health Literacy: When Understanding is Achieved

By: Margie Grieser, RN, CDDN

Health Literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed in order to make appropriate health decisions (Center for Health Care Strategies, Inc. 2013). Caregivers can consider that people with I/DD require varying degrees of assistance to achieve health literacy. Having health literacy results is the ability to use self-direction by practicing choice and control when deciding one's own health care strategy.

Previous articles in this series discussed obtaining and facilitating health information when working with people who have I/DD. Major principles from those articles were; assisting the individual with I/DD to locate accessible, understandable, concrete information, and prioritizing the information to answer the individual's questions. The caregiver can then facilitate the person's understanding of the information by using techniques such as allowing longer time for the individual to process the new information, assisting the individual to find and organize pictures depicting the health care topic and treatment, and repeating the information often, but avoiding giving too much information at one time.

This final article will offer pointers on how to assure the person has gained understanding, and how to assist the person to use the information to make a health care decision.

In order to confirm the person with I/DD is learning and retaining the health care information, it is important to observe the non-verbal responses of the person and the probable meanings. In general, human actions can communicate, "I get it," or "I don't get it" and "I am interested in learning about this," "I don't want to listen," or "I'm afraid." The caregiver can observe these non-verbal indications of successful or unsuccessful health literacy by using these suggested tips and tools:

- **Consider body language.** Is the individual focused; looking at you or the materials being introduced? Or, is the individual distracted and looking elsewhere? Is the individual leaning into the conversation and the educational materials; showing interest, or leaning back and away; showing disinterest?
- **Gestures.** Does the individual use gestures such as raised or furrowed eyebrows; showing concentration, or rolling the eyes; showing disbelief? Other gestures that may show disinterest such as rubbing the eyes, hand or finger waving.
- **Nods.** It is important to know the person you are supporting. Are they nodding their head in interest? Remember, people may nod but that does not always signify the information is being processed. It may be a tic or a way to show fatigue.

- **Facial Expressions.** What expression does the individual show when interested? Identify and consider the expressions to confirm the information is being heard and processed.
- **Sounds.** Individuals with I/DD can make noises to show excitement, fear, anxiety, or frustration. It is important to recognize and understand these sounds. Listen for grinding of teeth, deep breaths, holding of breath, whooping or coughing noises, loud noises, rapid speech or silence. These sounds, specific to each individual, can indicate that she or he is or is not understanding the information being presented.
- **Eye Contact.** If the individual is capable of maintaining some eye contact with you, the educator, consider that adequate eye contact can be an effective way of saying, “I am interested, I want to learn” or, wandering eyes may indicate a lack of interest. Remember that not everyone with I/DD is comfortable with eye contact, such as an individual with Autism Spectrum Disorder or Fragile X Syndrome, rendering it an unreliable indicator.
- **Language.** Has the individual with I/DD asked appropriate questions; showing understanding or made inappropriate comments; indicating a lack of understanding?
- **Peculiar Behaviors.** Adults with a significant sensory processing delay may have developed coping strategies which include peculiar behaviors or behaviors that are often misunderstood. This might include withdrawing from the opportunity for health education. Be sure to understand the behaviors of the person with I/DD as coping strategies to prevent them from being misinterpreted.
- **Mirroring.** Some may be able to repeat what has been said or to provide a return demonstration. This does not always indicate understanding. Individuals with I/DD can be very adept at copying what has been said or done, because most are eager to please the caregiver. Make every effort to distinguish between a “rehearsed answer”, and the answer given because health literacy is obtained through the individual’s understanding.

Assisting the Person to Make a Health Decision

At this point the caregiver will want to assist the person to make a health care decision, using the information obtained and processed. Here are some suggestions for assisting in the decision making:

- Ask the individual to make a decision regarding the health topic that has been learned. For example, consider the individual who may be learning about and preparing for a test to determine if dysphagia (difficulty swallowing), is present. The caregiver may ask, “Since we have spent time learning about having a swallowing test, what is your decision?” The individual may respond, “Yes, please schedule the test.” Or, “No, I don’t want to have this test.” The caregiver will want to explore the topic further if the individual responds negatively, only to assure understanding. *It is important to not assume the individual has little understanding of the topic because he did not give the response the caregiver would expect.*
- Help the individual with the decision making process by asking if there are any concerns or worries about the test. To help the individual to make an informed decision, understand and clarify any concerns expressed. One way is by asking the individual two questions: “What will happen if you have the test?” and “What will happen if you don’t?” Maybe, a potential change in one’s diet is a concern. Emphasize the outcome of the test and not the process. Present the information as positively as possible. The caregiver may say, “A new texture of your food can make it easier for you to swallow.”
- Make a simple list for a few positives and a few negatives using the individual’s own feedback, if possible. It may be beneficial to present the list as pictures that the person can understand.

If reminders of the process are necessary for the individual, it may be advisable to create a list of steps in order to clarify the test procedure. Then state the steps in chronological order. For instance; first, you go to the hospital and sign in with the receptionist. Second, you will meet with a speech pathologist. Third, you will sit in a chair. Fourth, the speech pathologist will offer you some bites to chew and swallow. This is not a detailed rehearsal guide; it is a reminder of the key steps in the process in order to trigger the person's memory to remind him of what to expect to make the day of the test easier for the person.

Another suggestion is to do a bit of local research. Is there another person from your agency or family living close by who had the same test? Is there a support group that can offer personal experiences? The person with I/DD may benefit from communicating with others and hearing their story about having a swallowing study. Maybe someone in their network of community supports can share their experience. Questions may be answered by calling the physician's office and asking the nurse to obtain health information on a more complicated test or procedure.

It is imperative to obtain, process, and understand basic health information in order to make health care decisions. People with I/DD may require assistance to obtain health literacy, and caregivers who implement the suggestions from this series of articles are equipped to provide that assistance. When health literacy is achieved, the person becomes an active member of the health care team and has a voice in health care decisions, giving them choice and control over their lives.



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Tips for Planning

Satisfying and Rewarding Experiences in the Community

By: Cheryl Pursley, RN, CDDN

Last spring's article 'Community Participation is Vital for an Everyday Life,' explained the importance for people with I/DD to experience various opportunities to participate in the community. The benefits for them are many and range from enhancing one's life experiences to engaging with others and forming social relationships.

Community participation such as employment, joining in activities with people we enjoy, or simply meeting a friend for coffee, are choices that most people take for granted. We explore different ideas that spark our interest, decide who we want to go with or to go alone, and make a plan to it carry out. We can decide on the spur of the moment to go to a movie or make extensive plans for a much needed vacation. People with I/DD want and should have these same opportunities to experience an "Everyday Life." Caregivers supporting people with I/DD should promote the person's desires and wishes to be included in the community and experience the same joys, sense of self-esteem, and friendships as people without disabilities. With a thoughtful plan for identifying and overcoming the barriers that may be present, a successful outcome can be achieved that is satisfying for the individual and gratifying for the caregiver. A careful plan includes:

- **Identify the person's wishes to participate in the community, be specific.** Many activities are planned based on the caregiver's ideas for the person, not the person's wishes.
- **Make a list of barriers that may interfere with the plan.** Barriers are person-specific such as the ability to pay for the activity, transportation, and health care issues.
- **List possible solutions to solve the barrier.**
- **Review and choose best possible solutions for each barrier.**
- **Create a plan to remove barriers.**
- **Implement the plan and ensure barriers along the way have been solved.**
- **Assess the outcome.** Did the plan work? Was the person happy with the outcome? Was the barrier removed and if not, what needs to be changed to remove the barrier?
- **Modify the plan if needed.** Plans for future activities can be based on this plan after modifications have been finalized.

Consider the below account of how a caregiver helped make a dream come true:

Val works a block shift on weekends and plans activities in the community for the two men in the group home she supports. She has taken them bowling, to the local bingo hall, and to various restaurants close by. Next month one of the men will be away for the weekend and Val will be working with Tony alone. She planned a fun night at a Mexican restaurant Tony likes followed by an hour playing bingo. Val explained her plan to Tony and was surprised that he didn't share her excitement. She asked him what was wrong and was surprised when Tony responded, "I want to do something different, I don't even like to play bingo. You never ask me what I want to do." Tony never expressed his dislike for bingo and this made Val feel awful. He was right; she never asked him what he wanted to do for fun. She apologized, asking him if he could do anything that weekend what would it be. He quickly replied, "I want to see the Pirates. I want to go to a real baseball game with all my friends on Pine St."

Val immediately felt overwhelmed with the prospect of planning this event. There were so many issues that needed to be addressed, but she was excited for Tony to experience his first baseball game. Val made a list of all the steps and obstacles that needed to be overcome in order to make that happen.

- Check the Pirates schedule and choose a day and time for the baseball game
- Choose seats
- Check the cost
- Transportation
- Call the house on Pine St. for their interest in attending the game
- Triggers for Tony related to his autism diagnosis and how to help him:
 - Crowds
 - Closeness of people
 - Sights, sounds, smells
 - Activity to keep him busy if he becomes bored
- The hot weather
- Food
- Bathroom run

Val called the group home on Pine St., explained her plan, and asked for feedback. The caregivers thought it was a great idea and three of their individuals were thrilled about going to the game. They discussed Val's list of possible barriers that may occur so they could troubleshoot ahead of time.

Val checked the Pirate's schedule. There was a Saturday night game and an afternoon game on Sunday when his housemate would be away. Due to the fireworks display scheduled after the night game she chose the Sunday afternoon game. (Fireworks scared Tony once causing him to run around holding his head screaming.) Val thoughtfully looked online at the seating chart. She looked for seats close to the bathrooms, on the end of a row, with only a few steps down the stairs to their seat. This would make it easy to reach their seats and get to the bathroom quickly if needed. Val searched online for the parking section and located the accessible parking areas. Pine St. had a van to accommodate everyone, with a pass for accessible parking. She called Pine St. group home and asked if a male caregiver would be attending as Tony would need help in the bathroom. Both Carl and Ben were working that weekend and could help out.

On the weekends she worked before the game, Val turned on the Pirate game and was surprised that Tony knew the strategy of the game and also the names of many prominent all stars. She asked Tony to listen closely to the noise of the crowd during the game and reminded him that people yell out and cheer loudly during the game. She told him he could cover his ears with his hands if the noise bothered him. Val also pointed out the close seating when the camera moved in showing the audience. They would be surrounded by other people. She also explained that people around them would be eating fragrant food like hot dogs,

hamburgers and fries. Tony had diabetes and was overweight, but Val wanted him to buy and enjoy food at the game. They discussed the foods he could eat and still follow his 1,800 calorie diet. He was excited to eat his first stadium hot dog!

The day of the game arrived and Tony began pacing and rocking, he was so excited. Val checked the weather, sunny and warm, perfect weather. Due to a side effect from one of his medications, Tony was sunburned a few times last summer. Before they left for the game she applied sunscreen and reminded him to bring his Pittsburgh Pirate baseball cap. She packed the sunscreen and his small model car that he like to hold when he was anxious or bored. Val sat down with Tony and reminded him again of the close proximity to the rest of the crowd, the noises and cheering, and the food he decided to buy.

Carl and Ben arrived in the van to pick up Tony and Val. The people from Pine St. were as excited as Tony and began singing "Take Me Out to the Ballgame" on the ride in. They arrived at their seats which were perfect for getting in and out easily and Tony sat on the end seat. While waiting for the game to begin, Tony began restlessly rocking in his seat. Val heard a small boy behind them ask his dad what Tony was doing. Val turned around and introduced Tony to him stating, "This is Tony's first baseball game and he is very excited."

With Val's help in recognizing all the obstacles that could take place with an outing to the ball game, Tony was well prepared. Val gave Tony his model car to hold until the game started and later when the crowd cheered after a home run, Tony put his hands over his ears. He loved the stadium hot dog he bought and because he drank a diet coke with no calories, he and Val shared a bag of popcorn. Carl accompanied Tony to the bathroom and while there applied more sunscreen. At the 7th inning stretch, Tony and his friends stood up and sang "Take Me Out to the Ballgame" loud and clear. By the 8th inning, everyone was getting tired and a bit restless. Val asked if they were ready to go home and all agreed they were. As they got up to leave the small boy sitting behind Tony smiled said "Bye Tony!" Tony leaned over, shook his hand and said goodbye. On the way home Tony and his friends from Pine St. talked excitedly about the game, the home run, and the good food. They listened to rest of the game on the radio and all cheered when the Pirates won. When they returned home, Tony was tired but still happy and excited. He continually thanked Val for the "best day ever!" Val promised Tony that they would definitely go again. It was rewarding for her to be in the position to arrange outings in the community and have such a positive influence on the lives of people she supports.

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Influenza (Flu)

By: Carrie Perrell, BSN, RN

This fall begins the 2017-2018 flu season. This article provides caregivers of people with I/DD and self-advocates basic information on the flu including ways to prevent the flu and how to care for a person who contracts the flu.

What is the flu?

Flu is an illness caused by viruses which affect the respiratory system. The respiratory system includes the nose, throat and lungs. The flu is contagious and is believed to be spread by droplets when an infected person sneezes, coughs or talks. When those droplets get into the mouths or noses of others, those individuals can become infected. If an infected person leaves droplets on surfaces, it is possible that another individual who touches those surfaces and then touches his or her own eyes, nose, or mouth can also become infected. A normally healthy person who gets the flu virus can infect others a day before that person has symptoms and then up to a week after becoming sick. Persons with weakened immune systems who get the flu can infect others for a longer period of time. Common flu symptoms include some or all of the following:

- Fever/chills
- Cough
- Runny nose
- Sore throat
- Muscle aches
- Tiredness

Individuals who have the flu may appear quite ill and it may not be difficult for caregivers to recognize that an individual is sick. However, for individuals who do not communicate with words, caregivers may observe behaviors such as being withdrawn, a lack of energy or enthusiasm, irritability, refusing to eat or drink, and grimacing during swallowing.

These symptoms are similar to cold symptoms. What is typically different when a person has the flu is that the flu symptoms will come on quickly and are usually more severe than cold symptoms. Muscle aches are common with the flu, as is a temperature over 100° F. Symptoms of the flu may improve over the course of two to five days, but some people feel run down for a week or more.

What is the concern about getting the flu?

Flu can cause mild to severe illness and in some cases can lead to death. Anyone, including healthy people, can get the flu. As well, anyone can experience complications from the flu. Complications include infections such as pneumonia, ear and sinus infections, and dehydration. Those who have chronic medical conditions such as asthma, congestive heart failure, or diabetes (to name a few) may see a worsening of those conditions. Individuals with I/DD may have a chronic illness. For example, many individuals with Down syndrome are born with heart disease. If those individuals get the flu, it can lead to a serious lung infection. Therefore, taking measures to prevent the flu is important to their health.

How can the flu be prevented?

The Centers for Disease Control (CDC) recommends getting an annual flu vaccine. As well, typical infection control measures such as hand washing, covering one's mouth when sneezing or coughing, and avoiding people who are sick are suggested. Eating healthy, getting adequate sleep, and managing stress may also help protect against getting the flu.

How does the flu vaccine work?

There are many different flu viruses. Research determines which flu viruses will be the most common during each upcoming flu season. Using this information, vaccines are then formulated. The most common flu viruses change year to year and this is why a person needs vaccinated for each new flu season.

Can't the flu vaccine cause the flu?

No. The flu vaccine viruses in vaccines are "inactivated" which means they are not infectious. However, a person could develop symptoms such as fever and aching muscles due to the body producing antibodies. Sometimes a person may still develop the flu because that person was exposed to the flu virus before the vaccination took full effect. It takes approximately two weeks following vaccination for a person to develop immunity.

It is possible to still get the flu—even if vaccinated—if the virus in the vaccine does not closely match the virus that ultimately circulates in the community. However, when this occurs the vaccine still may help many people prevent flu-related complications. This is because the person makes antibodies which still provide some protection against the flu virus.

Can I get the nasal spray flu vaccine and avoid a shot?

The CDC has suggested the nasal spray vaccine should not be used. This determination was made due to study of data from the past few years showing that the nasal spray was not every effective.

Can everyone get the vaccine?

The CDC recommends that everyone over the age of six months get the flu vaccine each year. There are special rare exceptions to this recommendation which include people who have severe allergies to any ingredient in the vaccine. There are special considerations for persons with egg allergies which may be discussed with the person's doctor. Persons who have ever had Guillain-Barre Syndrome (GBS) should discuss their history with the doctor prior to getting vaccinated.

What to do when a person gets the flu.

When a person over the age of 65 or any individual with a chronic illness gets the flu, caregivers would want to contact the person's physician for advice. The physician may want the individual to be treated with antiviral medications. These medications provide the greatest benefit when started within two days of becoming ill. There are side effects associated with these medications and in some circumstances the physician may not order them.

General treatment consists of making sure the person rests and has adequate fluid intake to avoid dehydration. The doctor may suggest the person takes medications as needed for fever and aches. A doctor's order is necessary for any medications given to a person in a group home.

The CDC recommends that a person who gets the flu stay home for a minimum of 24 hours after the fever is gone. Staying home when a person is infectious helps prevent spreading it to others in the community.

Do I need to see the doctor?

Follow agency policy with respect to this question. Generally speaking, a person who has a fever that lasts more than three days may have a secondary infection which will need treated. Severe throat pain may mean the person has strep throat, which requires medical attention. Coughs, congestion and headaches that persist could also be indicative of infections such as bronchitis or sinus infections.

Emergency attention is required for anyone who has shortness of breath, severe chest pain, severe headache, dizziness, confusion or persistent vomiting.

Summary

Flu season comes every year. Follow doctor's orders as far as immunizing against the flu and remember to always practice good hand hygiene. Washing your hands thoroughly with soap and water or using an alcohol based hand sanitizer when soap and water aren't available can help protect against getting the flu. Avoiding touching one's eyes, nose or mouth and avoiding crowds when flu outbreaks are occurring in your area can also help a person to avoid getting the flu.

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